

CenterLines

Center for Disabilities and Development *Useful News for Families*

The Disability Resource Library: Covering All the Bases

Mary Hubbard, Center for Disabilities and Development

From Allamakee county in the north to Mills county in the south, from Sioux county in the west to Lee county in the east, and all the counties in between... The Disability Resource Library (DRL) served clients in 62 Iowa counties last year. Our library is in Iowa City, but it can be as close as your phone or computer screen. You can get almost anything we have in the library at home. We lend to everyone at no charge for three weeks. There are more than 5,000 items waiting for you to choose.

Visitors to CDD can come and check us out; we are a family-friendly library. We are open every weekday from 9:00 a.m. to 5:30 p.m. Here you will find books and DVDs for all ages. If you want to learn about a disability issue we can help. Disability research is one of the things we can help

you do. Children have access to educational toys and activities on our big screen SmartBoard. We are so happy we added this to our library last spring.

Online visitors can get to us by going to our CDD website at www.uihealthcare.org/cdd and clicking on the link for the DRL under the Programs and Services section of the website. You can set up an account with us and order by e-mail from what you find online. Or, just give us a call and we will ship your items the next day. The only cost to you is to return the item through the mail.

Our website has a list of over 250 autism/Asperger's titles. Autism is a key topic. So are learning disorders, intellectual disabilities, and developmental issues. The library also has a full range of items on self-determination, independent living, and aging with a disability. You can try things out in the comfort of your own

home. We lend out software, computer peripherals, switches, and communication devices. This includes iPods as communication aids. Getting an iPod has helped people decide if it is the right device for them to communicate. Call us at 1-800-272-7713 to learn more about what the DRL can do for you. You can also e-mail us at disability-library@uiowa.edu.



University of Iowa Health Care



Language. . .It's Much More Than Words

Mike Hoenig, Center for Disabilities and Development

"How long have you been ... this way?" a friend asked recently.

Though I wanted to ask "which way?" I knew what she was asking.

"I've been blind all my life," I told her.

Whether they mean to or not, people tell us a lot about what they believe by the language they use. My friend was afraid to use the word "blind" because she thought she might hurt my feelings. As people living with disabilities, family members, and support people, it's up to us to teach others what language to use and how to treat us.

"I don't like it when our doctor calls my daughter Mayson a Down's kid," says Amy Flege of Ely. "Down syndrome does not define her. She does so many things that other five-year-olds do. It just might take her a little more time to do them. Old attitudes and labels like *retarded* (the R word) have to go!"

The use of respectful, positive language is just as important to Cherie Clark, a semi-retired disability rights activist with cerebral palsy from Cedar Rapids. "When people use words that make me feel different

because of my disability, I get very uncomfortable," she says emphatically.

"Having a disability doesn't make me handicapped, special, or courageous," Clark continues. And like Flege, she wants people to think of her as a *person* first.

"My husband and I own a home," Clark says. "I had a great career and still volunteer lots of time for things that are important to me. I pay taxes, vote, and love to go out to eat. To think of me and talk about me as someone who is *different* or *abnormal* is degrading and unacceptable."

Flege agrees. "When people learn that Mayson has Down syndrome, they say things like: 'I'm sorry' or 'She must have a mild case.' That tells me that they have lower expectations of her. She knows what she wants and needs. Like everyone else, she has her own ways of meeting those needs. It works for her!"

Using respectful language is not about being politically correct. It's about telling the person with a disability, the general public, and most importantly yourself that people with disabilities have the same hopes, skills, and talents as those who don't have disabilities.

"Change takes time," explains Flege, "and we understand that many people grew up expecting very little of people with disabilities. I don't want anyone to be afraid that they'll use the *wrong words*. All I ask is that you be open when I suggest a different way."

I couldn't have said it better myself!

Mini Guide to Respectful Language

Cut out and use as a bookmark!

People-First Language:

- ★ Ann has a disability
- ★ Joe uses a wheelchair
- ★ He has no disability
- ★ She has quadriplegia
- ★ He has a mental illness
- ★ Sam has Down Syndrome
- ★ Lisa has short stature
- ★ He has a brain injury

Old Language, disrespectful:

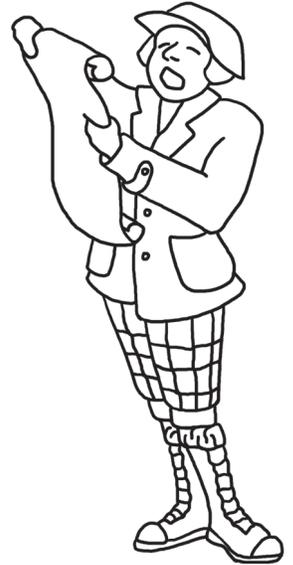
- ☹ *Handicapped*
- ☹ *Wheelchair bound*
- ☹ *Crippled*
- ☹ *Normal*
- ☹ *Crazy person*
- ☹ *A Downs kid*
- ☹ *A midget*
- ☹ *Brain damaged*



Learning Disabilities Association of Iowa

SCHOLARSHIPS FOR SPECIAL EDUCATION STUDENTS

Hear Ye, Hear Ye!



- ▼ Do you know of a 2012 high school graduate with an IEP?
- ▼ Would the student be a good candidate for a \$1000 scholarship?
- ▼ LDA-IA is offering three one-year scholarships to students with learning disabilities who plan to attend 2- or 4-year colleges or technical schools.

For more information go to the Learning Disabilities Association of Iowa website:

www.ldaiowa.org/Scholarships.asp



Speak Up and Ask!

There are two programs to get patients and families to take a bigger role in their own healthcare. One is called **Speak Up** from the Joint Commission. This is the group that makes sure that hospitals are safe.

There is another program called **Ask Me3**. It is from the National Patient Safety Foundation (NPSF). Patients and parents should know the answers to three questions after seeing a doctor:

1. **What is the main problem?**
2. **What do we need to do to help this?**
3. **Why is it important to do these things?**

You need to be sure to ask these questions if your doctor, nurse, or other specialist doesn't tell you. You also need to understand what they mean. You might be confused by some of the words and information you get. **Don't be embarrassed. Don't be afraid to ask them to explain.** Make sure they help you learn about the problem. They should give you more information or tell you where you can learn more about what they are saying.

Some places you can go to learn more about **Speak Up** and **Ask** are online. There are posters, brochures, and even videos on the web site of the Joint Commission. They come in English and Spanish:

www.jointcommission.org/speakup.aspx

The NPSF website also has brochures, videos, and checklists of things to ask.

www.npsf.org/for-patients-consumers/

www.npsf.org/for-patients-consumers/tools-and-resources-for-patients-and-consumers/checklist-for-getting-the-right-diagnosis/

When you come to CDD, remember to Speak Up and Ask if you need to know more or if something doesn't make sense. We are here to help you, and make sure you are safe and get the best healthcare.



Genetic Testing

Joni Bosch, Center for Disabilities and Development

Genes are building blocks built of DNA. They tell our bodies and brains how to grow. A mistake in our genes can cause a lot of problems.

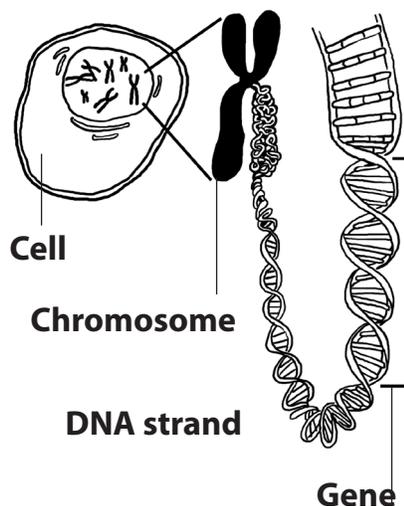
Genetic tests can sometimes tell us why someone has a problem with learning or growing.

If a person has a hard time learning, one test that might be ordered is a test for Fragile X syndrome. This is a gene problem that is passed on from mothers to their children. Fragile X syndrome is more common in boys. It happens when a gene gets turned off accidentally. Fragile X causes intellectual disability in boys. It can cause intellectual disability in girls, too, but girls are more likely to just have some learning problems.

Another common test is a CMA. This stands for “chromosomal microarray.” This test looks at all of our chromosomes in small chunks. It looks to see if we have too much or too little DNA in each chunk. Having too much or too little is called a CNV, or “copy number variant.” Too much DNA is called duplication. Not enough DNA is called a deletion. We all have some places where we have too much or too little DNA.

Some people have a CNV (too much or too little DNA) in important places. This can cause big problems. Down syndrome is caused by too much of chromosome 21. Turner syndrome is caused by having only one sex chromosome instead of two sex chromosomes. It is caused by not enough DNA.

Sometimes people have a CNV in a place that no one has talked about before. The Genetics doctors might not know whether or not that CNV is causing a problem. They might want to check the parents to see if they have that same CNV. If the parents don’t have any problems learning or growing and have the same CNV as their child, then the CNV might not actually be causing the problem.



These tests are helping us find a lot of genetic problems. They do not help us find all problems though. Neurofibromatosis 1 (NF1) can cause problems learning. The NF1 gene is made of a very long chain of DNA. A person can have NF1 if even one link of that DNA chain has a problem. A CMA will not pick up that kind of genetic problem. We need to do a different test called “DNA sequencing” to find that kind of problem.

Sometimes all the right links of DNA are there but they have a problem called “imprinting.” Imprinting turns specific genes on or off. If the gene accidentally gets turned off a person might have Prader Willi syndrome or Angelman syndrome. This can happen even if they have the right amount of DNA and the links are put together the right way.

Genes are really tricky. We have learned a lot about genes and DNA. There is still a lot more we don’t know. People can have genetic problems even if we cannot find them with genetic tests. A genetic test sometimes can tell us what causes a person’s problem, but not always.

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CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities,

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and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uihealthcare.org/cdd. Click on Centerlines for Families.

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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.